



Complete Summary

GUIDELINE TITLE

Palliative care.

BIBLIOGRAPHIC SOURCE(S)

Institute for Clinical Systems Improvement (ICSI). Palliative care. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI); 2008 May. 58 p. [113 references]

GUIDELINE STATUS

This is the current release of the guideline.

This guideline updates a previous version: Institute for Clinical Systems Improvement (ICSI). Palliative care. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI); 2007 Jan. 49 p.

** REGULATORY ALERT **

FDA WARNING/REGULATORY ALERT

Note from the National Guideline Clearinghouse: This guideline references a drug(s) for which important revised regulatory and/or warning information has been released.

- [November 8, 2007 and January 3, 2008 Update, Erythropoiesis Stimulating Agents \(ESAs\)](#): The U.S. Food and Drug Administration (FDA) notified healthcare professionals of revised boxed warnings and other safety-related product labeling changes for erythropoiesis-stimulating agents (ESAs) stating serious adverse events, such as tumor growth and shortened survival in patients with advanced cancer and chronic kidney failure.
- [October 24, 2007, Provigil \(modafinil\)](#): Cephalon has agreed to include additional labeling revisions to the WARNINGS, CLINICAL PHARMACOLOGY, PRECAUTIONS, and PATIENT PACKAGE INSERT sections.
- [September 17, 2007, Haloperidol \(Haldol\)](#): Johnson and Johnson and the U.S. Food and Drug Administration (FDA) informed healthcare professionals that the WARNINGS section of the prescribing information for haloperidol has been revised to include a new Cardiovascular subsection.

COMPLETE SUMMARY CONTENT

** REGULATORY ALERT **

SCOPE

METHODOLOGY - including Rating Scheme and Cost Analysis

RECOMMENDATIONS
EVIDENCE SUPPORTING THE RECOMMENDATIONS
BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS
QUALIFYING STATEMENTS
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INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT
CATEGORIES
IDENTIFYING INFORMATION AND AVAILABILITY
DISCLAIMER

SCOPE

DISEASE/CONDITION(S)

Potentially life-limiting, life-threatening or chronic, progressive illnesses that might benefit from palliative care

GUIDELINE CATEGORY

Management

CLINICAL SPECIALTY

Cardiology
Family Practice
Geriatrics
Internal Medicine
Neurology
Oncology
Pediatrics
Pulmonary Medicine

INTENDED USERS

Advanced Practice Nurses
Allied Health Personnel
Health Care Providers
Health Plans
Hospitals
Managed Care Organizations
Nurses
Patients
Physician Assistants
Physicians
Social Workers

GUIDELINE OBJECTIVE(S)

- To increase the identification of patients who are in the early stages of a progressive, debilitating disease who would benefit from palliative care services

- To improve the effectiveness and comfort level of the primary care provider in communicating the necessity and benefits of palliative care with those patients with a progressive, debilitating illness
- To improve the assessment of the identified patient's palliative care needs utilizing the seven domains of palliative care
- To increase palliative care planning with patients who have been identified in the early stages of a progressive debilitating disease
- To improve the continual reassessment and adjustment of the patient's palliative care plan as conditions warrant, utilizing the seven domains of care
- To increase the completion, documentation and ongoing utilization of advance directives for patients with a progressive, debilitating illness

TARGET POPULATION

Adult patients with potentially life-limiting, life-threatening or chronic, progressive illness who might benefit from palliative care including patients who still desire curative or life-prolonging treatments and those who are best served by active end-of-life management

Note: This guideline will not assist providers in the identification or care for pediatric patients with life-threatening or chronic progressive illness. Within the guideline there is a brief overview of the Special Considerations for Pediatric Patients.

INTERVENTIONS AND PRACTICES CONSIDERED

1. Initiation of palliative care discussion
2. Assessment of palliative care needs and values with care conferences
3. Management of physical aspects such as pain, anxiety and depression, anorexia and cachexia, constipation, delirium, diarrhea, dyspnea, fatigue, nausea and vomiting
4. Management of cultural, psychological, social, spiritual, religious, existential, ethical, and legal aspects of care
5. Development and implementation of palliative care plan
6. Hospice care
7. Palliative and specialty care referrals and consults as needed
8. Managing imminently dying patients and bereavement process

MAJOR OUTCOMES CONSIDERED

Efficacy of palliative care

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

A literature search of clinical trials, meta-analysis, and systematic reviews is performed.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Classes of Research Reports:

A. Primary Reports of New Data Collection:

Class A:

- Randomized, controlled trial

Class B:

- Cohort study

Class C:

- Non-randomized trial with concurrent or historical controls
- Case-control study
- Study of sensitivity and specificity of a diagnostic test
- Population-based descriptive study

Class D:

- Cross-sectional study
- Case series
- Case report

B. Reports that Synthesize or Reflect upon Collections of Primary Reports:

Class M:

- Meta-analysis
- Systematic review
- Decision analysis
- Cost-effectiveness analysis

Class R:

- Consensus statement
- Consensus report
- Narrative review

Class X:

- Medical opinion

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

New Guideline Development Process

A new guideline, order set, and protocol is developed by a 6- to 12-member work group that includes physicians, nurses, pharmacists, other healthcare professionals relevant to the topic, along with an Institute for Clinical Systems Improvement (ICSI) staff facilitator. Ordinarily, one of the physicians will be the leader. Most work group members are recruited from ICSI member organizations, but if there is expertise not represented by ICSI members, 1 or 2 members may be recruited from medical groups or hospitals outside of ICSI.

The work group will meet for seven to eight three-hour meetings to develop the guideline. A literature search and review is performed and the work group members, under the coordination of the ICSI staff facilitator, develop the algorithm and write the annotations and footnotes and literature citations.

Once the final draft copy of the guideline is developed, the guideline goes to the ICSI members for critical review.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

The guideline developers reviewed published cost analyses.

METHOD OF GUIDELINE VALIDATION

Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Critical Review Process

Every newly developed guideline or a guideline with significant change is sent to the Institute for Clinical Systems Improvement (ICSI) members for Critical Review. The purpose of critical review is to provide an opportunity for the clinicians in the member groups to review the science behind the recommendations and focus on the content of the guideline. Critical review also provides an opportunity for clinicians in each group to come to consensus on feedback they wish to give the work group and to consider changes necessary across systems in their organization to implement the guideline.

All member organizations are expected to respond to critical review guidelines. Critical review of guidelines is a criterion for continued membership within ICSI.

After the critical review period, the guideline work group reconvenes to review the comments and make changes, as appropriate. The work group prepares a written response to all comments.

Approval

Each guideline, order set, and protocol is approved by the appropriate steering committee. There is one steering committee each for Respiratory, Cardiovascular, OB/GYN, and Preventive Services. The Committee for Evidence-based Practice approves guidelines, order sets, and protocols not associated with a particular category. The steering committees review and approve each guideline based on the following:

- Member comments have been addressed reasonably.
- There is consensus among all ICSI member organizations on the content of the document.
- Within the knowledge of the reviewer, the scientific recommendations within the document are current.
- Either a critical review has been carried out, or to the extent of the knowledge of the reviewer, the changes proposed are sufficiently familiar and sufficiently agreed upon by the users that a new round of critical review is not needed.

Once the guideline, order set, or protocol has been approved, it is posted on the ICSI Web site and released to members for use. Guidelines, order sets, and protocols are reviewed regularly and revised, if warranted.

Revision Process of Existing Guidelines

ICSI scientific documents are revised every 12 to 36 months as indicated by changes in clinical practice and literature. Every 6 months, ICSI checks with the work group to determine if there have been changes in the literature significant enough to cause the document to be revised earlier than scheduled.

Prior to the work group convening to revise the document, ICSI members are asked to review the document and submit comments. During revision, a literature

search of clinical trials, meta-analysis, and systematic reviews is performed and reviewed by the work group. The work group will meet for 1-2 three-hour meetings to review the literature, respond to member organization comments, and revise the document as appropriate.

If there are changes or additions to the document that would be unfamiliar or unacceptable to member organizations, it is sent to members to review prior to going to the appropriate steering committee for approval.

Review and Comment Process

ICSI members are asked to review and submit comments for every guideline, order set, and protocol prior to the work group convening to revise the document.

The purpose of the Review and Comment process is to provide an opportunity for the clinicians in the member groups to review the science behind the recommendations and focus on the content of the order set and protocol. Review and Comment also provides an opportunity for clinicians in each group to come to consensus on feedback they wish to give the work group and to consider changes needed across systems in their organization to implement the guideline.

All member organizations are encouraged to provide feedback on order sets and protocol; however, responding to Review and Comment is not a criterion for continued membership within ICSI.

After the Review and Comment period, the work group reconvenes to review the comments and make changes as appropriate. The work group prepares a written response to all comments.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Note from the National Guideline Clearinghouse (NGC) and the Institute for Clinical Systems Improvement (ICSI): For a description of what has changed since the previous version of this guidance, refer to [Summary of Changes Report -- May - 2008](#).

The recommendations for palliative care are presented in the form of an algorithm with 22 components, accompanied by detailed annotations. An algorithm is provided for [Palliative Care](#); clinical highlights and selected annotations (numbered to correspond with the algorithm) follow.

Class of evidence (A-D, M, R, X) ratings are defined at the end of the "Major Recommendations" field.

Clinical Highlights

- Palliative care planning should begin early in the patient's journey of a progressive, debilitating illness. A key question for providers is "would you be surprised if the patient died within two years?" (*Annotation #1*)
 - Where palliative care consultation is available, referral to this service should be done early on in the patient's care.
 - Where palliative care services are not available, primary care providers should begin palliative care planning early.
- Health care providers should initiate palliative care conversations with their patients. (*Annotation #3*)
- Health care providers should complete a systematic review and document patients' goals for care and advance directives. (*Annotation #4*)
- Suffering is common in this patient population. It commonly presents itself in physical symptoms, thus controlling symptoms to maximize patient comfort is a cornerstone function of palliative care. Also important are the recognition, assessment, and management of non-physical areas of suffering that are important to the patient. These include cultural, psychological, social, spiritual, religious, existential, financial, ethical and legal issues. (*Annotations #5-11*)
- The ability to address these issues depends on the quality of communication with patients and families. Communication difficulties among health care providers, patients, and families can hamper quality of care and patient well-being. Setting realistic goals of care and providing realistic hope are essential. (*Annotation #3*)
- In the delivery of palliative care, aggressive interventions may continue with an increased focus on symptom management. (*see Introduction section in the original guideline document*)
- Health care providers play an important role in the grief and bereavement processes by supporting the patient and family throughout the course of illness and following the patient's death. (*Annotation #22*)

Palliative Care Algorithm Annotations

1. Patient Presents with New or Established Diagnosis of a Progressive, Debilitating and/or Potentially Life-Limiting Illness

Key Points:

- Both providers and patients generally don't recognize early on those individuals who would benefit from palliative care planning.
- Early identification of patients with conditions that would benefit from palliative care planning can be accomplished by considering conditions and symptoms that are appropriate for palliative care services.

General considerations clinicians should use to identify patients who would benefit from palliative care planning include:

- Disease progression, especially with functional decline
- Pain and/or other symptoms not responding to optimal medical treatment
- Need for advance care planning
- Guideline met for hospice eligibility, but "not ready"

Conditions that may prompt palliative care planning include debility/failure to thrive, cancer, heart disease, pulmonary disease, dementia, liver disease, renal disease, neurologic disease such as stroke, Parkinson's, amyotrophic lateral sclerosis (ALS), and multiple sclerosis (MS). For more information on these conditions refer to the original guideline document.

Many residents in long-term care facilities have these conditions and should be assessed for palliative care.

The work group offers a comparison of Conditions and Symptoms appropriate for Palliative and Hospice Care. See Appendix A in the original guideline document.

Unfortunately, accurately predicting death can only be identified by retrospective measures. Multiple studies have shown that physicians overestimate prognosis by a factor of two or more. The medical literature also shows that patients with terminal illness don't recognize that they are dying, or are unable to acknowledge the fact even to themselves until very late. Life-limiting illness is usually defined as the question *"Would you be surprised if your patient died within the next two years?"* This definition significantly broadens the identified population associated with hospice care to those who would benefit from palliative care. Appropriate medical interventions need to address suffering that occurs due to pain, and other physical symptoms, and psychological issues. Other domains that should be addressed by an interdisciplinary team include cultural, spiritual, ethical and social issues. The care plan created includes the caregivers and family [R]. Palliative care can occur simultaneously with curative therapies, or may be the sole focus of care.

2. Imminently Dying Patient Presents

See Annotation #11 for care of the imminently dying patient.

Key Points:

- Providers should recognize patients with signs of imminent death or those patients who are receiving futile care.
- Providers should discuss the likelihood of disease progression to death with patients and their families.

Diagnosing dying is a complex process. Physicians are frequently inaccurate about the length of time left to a patient before he/she dies. Each individual patient is different. Physicians are trained to cure patients and will often continue aggressive, invasive procedures and treatments at the expense of making the patient comfortable. There is often a reluctance to make the diagnosis of dying if any hope of improvement exists and even more so if no definite diagnosis has been made. When recovery is uncertain, it is better to discuss this rather than giving false hope to the patient and family [B], [D].

This portion of the guideline is meant to aid providers in identifying those patients imminently dying or those to whom aggressive therapy is no longer

the best option. These patients may not have been previously identified as palliative care patients.

The following signs and symptoms may indicate that death is approaching. Not all individuals will show all of these signs.

- Delirium, often manifested by increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently.
- Withdrawal from active participation in social activities.
- Increased periods of sleep, lethargy.
- Decreased intake of food and liquids.
- Periods of pausing in breathing (apnea) whether awake or sleeping. Very rapid breathing or cyclic changes in the patterns of breathing (Cheyne-Stokes respirations). Other abnormal breathing patterns.
- Patient reports seeing persons who have already died.
- Patient states that he or she is dying.
- Patient requests family visit to settle unfinished business and tie up loose ends.
- Inability to heal or recover from wounds or infections.
- Increased swelling (edema) of either the extremities or the entire body.
- Inability to arouse patient at all (coma) or ability to arouse patient only with great effort, but patient quickly returns to severely unresponsive state (semicoma).
- Severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality.
- Increased respiratory congestion or fluid buildup in the lungs. Shortness of breath.
- Inability to swallow any fluids at all. Not taking food by mouth. Vomiting.
- Patient breathing through wide open mouth continuously and no longer can speak even if awake.
- Urinary or bowel incontinence in a patient who was not incontinent before.
- Marked decrease in urinary output and darkening color of urine or very abnormal color of urine, such as red or brown.
- Blood pressure dropping dramatically from patient's normal blood pressure range (more than a 20- 30 point drop).
- Systolic blood pressure below 70. Diastolic blood pressure below 50.
- Patient's extremities feel very cold to the touch.
- Fever.
- Patient complains that his or her legs/feet are numb and cannot be felt at all.
- Cyanosis, or a blue or purple coloring to the patient's arms and legs, especially the hands and feet (mottling).
- Patient's body is held in a rigid unchanging position.

3. Initiate Palliative Care Discussion

Key Points:

- The ability to frankly discuss and plan with patients and families is as important as any other medical interventions.
- Practice and experience with discussions about end-of-life decisions and palliative care will improve providers' skill and comfort levels.
- There are several "scripts" that can be used both in practicing and in actual conversations.

Many providers feel they lack confidence and experience in discussing with patients the issues and decisions that come with having a progressive, debilitating illness – specifically recommendations about palliative care and hospice services.

There are several excellent mnemonics available to help providers increase their knowledge, practice examples of these discussions, and generally obtain a better understanding of the emotions, questions and problems that may arise with patients and families at this time in their lives.

One mnemonic found useful for this guideline includes:

- ABCDE (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions) [R]

Advance preparation: Obtain the patient's medical information and test results, if possible, so that you are fully aware of the situation. Mentally rehearsing the way you wish to present the information and options can give you a sense of how the conversation may go. Remember to individualize your approach for each given patient based on how much they know at that point and how they prefer to receive information. Make sure that you have an appropriately private location in which to have the discussion and that the session will be free of interruptions, including setting the pager to silent or leaving it with a colleague.

Build a therapeutic environment/relationship: Try to find out how much the patient and family understands, how they want to be told (bluntly, gently, etc.), and how much they want to know at that time.

- "If this condition turns out to be something serious, are you the kind of person who likes to know what is going on?"
- "Would you like me to tell you the full details of the diagnosis?"
- "If your condition is serious, how much would you like to know?" If the patient indicates that he/she does not want any information, it is important to "leave the door open." For example you may say, "That's OK. If you change your mind, at any time, please feel free to talk to me or one of my colleagues."
- Have family members or friends present as per the patient's preference, and take time to learn names and relationships of each support person present. Use touch and humor where appropriate, taking into consideration your relationship with the patient. Reassure the patient of your availability, set up follow-up appointments, and contact other providers about the situation where appropriate.

Communicate well: Ask the patient for any questions. Speak truthfully but compassionately and avoid using medical terms or euphemisms. Say the words cancer, dying, death, etc.

Adapt the communication style to the education level and personal preference of the patient and family. For example, if the patient is a company executive who is used to calling the shots, this person may benefit more if provided with several different options to choose from rather than being told what to do [R]. If the education level and preferred style are unknown, a good rule of thumb is to present information at a sixth through eighth grade level [R].

Don't rush the process; allow time for silence, tears and questions. Remember that the patient may not retain much of the information given past that of the diagnosis or prognosis, and may have to wait to "digest" what information can be absorbed. Strong emotions elicited in difficult conversations may distract the patient from hearing the full communication. Repeat important points and write things down and periodically assess the patient's understanding of the information and reactions to what was heard [R]. Think out loud; help the patient and family feel they are part of the team. Visual aids, written question prompts (suggesting possible questions that a patient or family may want to ask), and the provision of audio tapes of the conversations may aid communication and recall of important points.

Communicate any bad news to the patient and family. The care provider may want to deliver a "warning" statement prior to the bad news itself to prepare the patient (and family if present) for the communication that follows. For example, "I'm afraid I have (difficult/bad) news to share on (his/her) condition" [R]. Additionally, it may be advisable to ask a few open-ended questions prior to delivering the actual bad news to assess what the patient and family already know and their readiness to hear the news [R].

Deal with patient and family reactions: Be sensitive to the emotional reactions of the patient and family. Recognize that denial, blame, intellectualization, disbelief, and acceptance may be present to varying degrees and time frames. Watch for signs of depression and suicidality in subsequent visits. Be empathetic. Crying may occur but make sure that your tears are empathic in nature and not reflective of personal issues on your part. There may be anger from the patient and family about care received from you or another colleague; resist becoming defensive or argumentative about these issues. Try to deal with that particular patient's and family's cultural and ethnic norms.

- "I was probably raised differently than you. Can you tell me how your family deals with these situations?"

Encourage and validate emotions: During the discussion, periodically ask the patient and family how and what they are feeling and respond with empathy. If the patient (and family if present) is ready, discuss treatment options and arrange for follow-up to put those options into action. Talk with the patient about what this means for him/her, and what needs outside of the traditional medical scope he/she may have. It is important that the patient and family do not lose their sense of hope. Offer realistic hope. Communicating hope, even

though a "cure" may not be possible, may be done by redirecting the focus of hope to keep the patient comfortable and as symptom-free as possible. Reassure the patient that every effort will be made to promote comfort, dignity and quality of life as defined by the patient.

- "I know this is not what you wanted to hear."
- Don't say, "*There is nothing more we can do*;" instead say, "What we are going to focus on now is___ (comfort, pain relief, etc.)" [R].

See Appendix B, "Myths about Palliative Care" in the original guideline document.

Refer to the original guideline document for additional considerations pertaining to palliative care discussion.

4. Assessment of Patient's Palliative Care Needs and Values

Key Points:

- Use of a consistent, validated assessment tool enhances care.
- Thorough assessment should be based on the domains of palliative care and address needs, values and resources.
- Documentation and periodic review of the patient's goals and plan of care are essential.
- Periodic reassessment and revision of the care plan should be incorporated into care conferences to assure ongoing communication among the patient, family and health care team.
- Children and their families are a special population with special palliative care needs.

Palliative care planning should begin at the time of diagnosis of a life-threatening or debilitating condition and continue through cure, or until death and then into the family's bereavement period. Good palliative care, as part of any good health care provision, requires continual reappraisal of the benefits and burdens of therapies [D].

It is important, especially in the development of recommendations for care of patients' palliative care and end-of-life needs, that there is recognition of patient autonomy in choosing care [R]. One goal of this annotation is to discuss how clinicians can create an environment in which the needs of the patient, based on a comprehensive assessment, are fully considered. Only then can a reasonable determination be made of what services are required to meet the physical, psychological, social, practical and spiritual needs of patients and their families. Providers recognize that assessment of these domains of care is important to a patient's care but, in a busy practice, may find it difficult to address all domains. The work group recognizes this and suggests that clinicians could incorporate key aspects of palliative assessment with existing assessment processes. They also encourage using a team approach. Routine assessment has been shown to identify symptoms that may otherwise have been overlooked or unreported, facilitate treatment and treatment planning, and enhance patient and family satisfaction [R].

For patients to make informed choices regarding palliative care, it is important for both patient and providers to have a realistic understanding of the options available. The patient must have the capacity to understand the choices available, especially when some of the choices are not likely to benefit the patient to any great extent. Further, it should be recognized by providers and communicated to patients that the realistic choices available for care may change as the patient's medical condition changes. Accordingly, assessment of palliative care needs will necessarily be ongoing and may require at some point, if the patient's mental capacity is impaired, the assistance of family or other well-informed surrogates to provide the information needed to assess the patient's ever-changing palliative care needs. The role of surrogate for assessment of patient condition and expression of patient wishes should be anticipated at the time of initial assessment and care planning. Bringing together, as much as possible, those who may impact decision-making should be integral to the initial plan of care development. Careful clarification for all present at initial care planning will help anticipate and prevent discord as the patient and surrogate(s) make future care choices. The initial meeting for care planning is also useful for identifying availability and limitations of caregivers and other resources for meeting patient needs in implementing the plan of care.

Patient and family expectations, goals for care and for living (quality of life), understanding of the disease and prognosis, as well as preferences for the type and site of care should be assessed and documented. This assessment needs to be reviewed on a regular basis, with consideration given to the patient's capacity to represent himself/herself.

Care Conferences

Patient and family meetings or care conferences allow the treatment team an opportunity to meet with the patient and/or family to discuss the patient's diagnosis, condition, course of illness and treatment options and to answer questions and establish both the goals and plan of care. The level of formality of these conferences is likely to vary depending on the focus or goals. These conferences may involve the primary provider and part of the care team or the entire team.

There is little empirical evidence and there are few descriptive studies about family care conferences or meetings. Most guidelines for care conferencing are based on expert recommendations. Family counseling literature and studies of giving bad news and end-of-life discussions form the basis for these expert recommendations [D], [R].

A step-by-step model for care conferences [Not Assignable] outlines four goals for a family meeting or conference. These goals focus on:

- Gaining knowledge of the person experiencing illness and understanding this person's goals
- Promoting communication between the care team and patient/family
- Decreasing stress and suffering by reviewing realistic goals and establishing a realistic plan that aligns with these goals

- Establishing trust and support to work with the patient/family throughout the course of illness

Incorporating time for this assessment can be done in either the inpatient, outpatient or home settings. In the inpatient setting, this assessment may be done by the palliative care team or by the physician during daily rounds. In the outpatient setting, this assessment can be accomplished over a series of visits or during an extended visit. In the home setting, this can be accomplished in one or more home visits.

At present, there is no gold standard for assessment of symptoms in the palliative care population [R]. Among the available assessment tools, it was the decision of this work group to recommend the Edmonton Symptom Assessment System (ESAS) because it is readily available via Internet, it is thorough yet simple in clinical application, and it has a robust evidence-based foundation for validation in various clinical settings [D].

As patient and provider conditions change, there may be need for change of site or providers of care. It is helpful in care planning if the community has a uniform system to communicate patient wishes so that the continuity of care makes a smooth transition between providers in these circumstances. In this regard, communitywide agreement on recognition of particular advance directive forms and Physician Orders for Life-Sustaining Treatment (POLST) enhances the quality of care available.

See the Support for Implementation, Other Resources Available section in the original guideline document for the POLST and ESAS Web sites.

Documentation of the advance directive in an electronic medical record promotes accessibility and portability across care settings.

Providers should be aware of their individual state, provincial or national forms and requirements.

For more information, see Annotation #10, "Ethical and Legal Aspects of Care."

Special Considerations for Pediatric Patients

- Children with life-limiting diseases and their families benefit from pediatric-specific palliative care services.
- It is important to manage developmental level concerns, as well as symptoms needing to be addressed.
- There are specific ethical and legal concerns related to the pediatric population.

The Initiative for Pediatric Palliative Care (IPPC) provides both an education and a quality improvement effort, aimed at enhancing family-centered care for children living with life-threatening conditions. IPPC's comprehensive, interdisciplinary curriculum addresses knowledge, attitudes and skills that

health care professionals need in order to better serve children and families. These include:

- **Engaging with children and families** – enhancing the ability of health care professionals to understand, support and engage effectively with children with life-threatening conditions, their parents and loved ones, reflecting on core principles in pediatric palliative care and discovering what matters most to families, by incorporating the perspectives of children and families in treatment.
- **Relieving pain and other symptoms** – by learning competent assessment, documentation, reassessment and continuously monitoring of a pediatric patient's pain and other symptoms using developmentally appropriate pain assessment tools and strategies.
- **Analyzing ethical challenges in pediatric end-of-life decision-making** – learning methods to support families as they confront an array of difficult choices often encountered when a child is gravely ill and unlikely to recover. This includes ethical recommendations for guiding decisions regarding withholding or withdrawing of life support to allow natural death and strategies for handling circumstances in which parents and clinicians may disagree about goals of care. It includes the degree of benefit and burden associated with different treatment (and not treating) options, the importance of honoring parental discretion in decision-making, especially when there are uncertain benefits associated with the continuation of life-prolonging treatments, the legitimacy of quality of life considerations in goal setting, how to handle conflicts, and the extent to which mature minors should be able to guide their own decisions. Other topics include the use or forgoing of artificial nutrition and hydration, as well as ethical issues relevant to the treatment of pain and suffering, such as those related to palliative sedation.
- **Responding to suffering and bereavement** – enhances the ability of health care professionals to recognize, validate and respond to suffering in children, parents and family members, by developing a perspective from which to understand and respond to the suffering and bereavement experience of children and families and how this interconnects with their own experience as professional caregivers. The potential contribution of palliative care to provide critical support to the dying child and grieving family members cannot be overstated.
- **Improving communication and strengthening relationships** – enhances health care professionals' communication and relational skills, specifically pertaining to what is known about working with children and families, including a cross-cultural undertaking in which the challenge is to understand and respond to the practices of the family [R]

5. Physical Aspects of Care

See ICSI Palliative Care Order Set for specific medications and dosages.

Key Points:

- Anticipate symptom progression, assessing needs and efficacy of interventions as disease progression occurs, and adjust interventions accordingly.
- Use a team approach to care when possible and appropriate.
- Symptom control is important, but suffering is much broader than just physical symptoms.

Physical Aspects of Care

The control of physical symptoms is an important part of palliative care. Common symptoms include, but are not limited to pain, anxiety and depression, anorexia and cachexia, constipation, delirium, diarrhea, dyspnea, fatigue, and nausea and vomiting.

Pain

Control of pain in order to improve quality of life is an important aspect of palliative care.

Pain is a subjective symptom; there is no test to measure pain. Pain is what the patient says it is, and it needs to be addressed adequately in order to improve quality of life. The patient should be actively involved in establishing the goals of palliative pain management, along with family members. **The clinician should frequently reassess the patient's desired level of comfort and response to interventions.**

Patients and family members should be educated about medication compliance, addiction, tolerance, side effects and appropriate dosing of analgesics. Many patients, as well as family members, believe the use of opioids will create "addicts" and so are reluctant to use opioids for analgesia. All opioids will result in physical dependence, and sudden discontinuation of the opioid may result in symptoms of withdrawal. Physical dependence is not addiction. Addiction, as defined by the Federation of State Medical Boards of the United States, is "a primary, chronic, neurobiologic disease...characterized by behaviors that include the following: impaired control over drug use, craving, compulsive use, and continued use despite harm." Pseudoaddiction may occur when analgesics are prescribed inadequately. When the interval between doses of opioids is too long, a patient's pain relief may wane, resulting in the need to ask for more medication. This request, sometimes perceived as "drug-seeking behavior," is actually a consequence of poor prescribing habits.

Barriers to good pain management in palliative care include discounting a patient's subjective measure of pain, difficulty in assessment of the cognitively impaired, myths believed by both practitioners and patients about opioid therapy, and fears of addiction and hastening death.

A thorough assessment of the patient should distinguish whether the patient has visceral, somatic or neuropathic pain. Recommendations and options for treatment of each type of pain can be found in the National Guideline Clearinghouse (NGC) summaries of the Institute for Clinical Systems

Improvement (ICSI) guidelines [Assessment and Management of Acute Pain](#) and [Assessment and Management of Chronic Pain](#).

Anxiety and Depression

Affective disorders such as anxiety and depression are common in seriously ill patients, and they adversely affect their quality of life. Not only can they cause physical symptoms such as nausea, dyspnea and insomnia, but conversely, experiencing such symptoms can exacerbate anxiety, as well. Undertreated pain can exacerbate psychological distress.

Benzodiazepines are often helpful in the treatment of anxiety. Lorazepam and oxazepam are preferred since they do not have active metabolites. A significant minority of individuals manifest a paradoxical reaction to benzodiazepines, becoming more agitated. Chronic anxiety frequently responds to the use of serotonin-specific or serotonin-norepinephrine re-uptake inhibitors.

Diagnosing depression can be challenging because many of the typical somatic symptoms such as fatigue, insomnia and anorexia can be caused by the underlying medical illness or by normal grief. Psychological symptoms such as apathy, anhedonia and feelings of worthlessness and hopelessness may suggest the diagnosis. Although a variety of helpful depression assessment questionnaires and tools exist, the clinical interview is still the gold standard for diagnosis of depression [R].

It is important to differentiate grief from depression. Grieving can be an appropriate response to loss, but persistence of the above symptoms mandates consideration of depression. Simply asking a patient, "Are you depressed?" can be a useful screening tool and provides a reasonably sensitive and specific assessment of depression in patients with terminal illnesses [R]. However, this may be preceded by some information to the patient about the difference between clinical depression and appropriate reactive feelings to the situation. The clinician must inquire if the patient is at risk for suicide. There is no evidence that asking the patient about suicide increases the risk that the patient will carry out his or her plan.

In depression, serotonin-specific re-uptake inhibitors are drugs of first choice, including in older and frail patients. However, it may take weeks to fully respond. Psychostimulants such as methylphenidate can produce a more rapid response and are well tolerated in most patients. In patients with a life expectancy of more than a few weeks, a successful therapeutic trial of psychostimulants should be accompanied or followed by an antidepressant medication such as a serotonin-specific re-uptake inhibitor [R]. Because antidepressant drug treatment is usually well tolerated, some expert consensus statements recommend a low threshold for instituting treatment, although evidence from primary studies on the effectiveness of antidepressants at the end of life is poor. Evidence regarding the pharmacologic treatment of anxiety in the palliative care setting is similarly limited [R].

Nonpharmacologic measures for affective disorders are often beneficial and should not be overlooked. A combination of antidepressant medications, supportive psychotherapy, and patient and family education are considered the gold standard of treatment of depression in palliative care. Cognitive therapy may also be helpful in some circumstances. Studies in psychotherapy in depressed palliative care patients have shown equivocal results, but data are limited by small sample sizes, short follow-up periods, and high diversity of outcome measures used [R].

Anorexia and Cachexia

Anorexia refers to the loss of desire to eat, while cachexia refers to weight loss, especially of lean body mass, which may significantly impair the patient's ability to continue with further therapy. Both these symptoms are found in many severe medical conditions, including cancer, acquired immunodeficiency syndrome (AIDS), chronic obstructive pulmonary disease, congestive heart failure, chronic liver and kidney disease, and infections.

Treatable causes of anorexia and cachexia should be identified and addressed. Causes may include pain, depression, gastrointestinal tract dysfunction, and cognitive impairment. Stimulation of appetite through the use of progestones and corticosteroids may help. One study suggests that doses of 160 mg to 800 mg per day of megestrol acetate have demonstrated a positive effect on appetite and food intake [A]. Other studies have shown that while megestrol produces weight gain, the increase is due to fat and not lean muscle mass [A], [R]. Progestational agents may be associated with an increased risk of thromboembolic events, peripheral edema, hyperglycemia, hypertension, hypogonadism, and adrenal suppression. In order to minimize these adverse effects, doses of megestrol acetate should start at 160 mg daily, and be increased every two weeks until benefit is seen, or until side effects limit further dose escalations [R]. For most conditions, there is scant information about improved quality of life, and no survival benefit has been shown.

Corticosteroids may provide a temporary improvement in appetite and food intake. However, because of significant side effects, these drugs should probably be reserved for the terminally ill, and in those patients who may simultaneously benefit from the antiemetic and analgesic properties of the steroids.

Other agents showing some positive effects on appetite and weight gain include mirtazapine in depression, thalidomide in advanced cancer and AIDS, dronabinol in AIDS and anabolic steroids in chronic obstructive pulmonary disease (COPD) and AIDS [C], [R].

Patients sometimes describe poor appetite when presented food that is unappealing in appearance, consistency or smell. Minimizing dietary and consistency restrictions may tempt the patient to improve his or her intake. Offering small quantities more frequently throughout the day may also promote better intake.

In some cases the patient is less troubled than the family by poor nutritional intake. Clinicians should explore the meaning of feeding in the context of the family's cultural and religious background, and help identify other ways in which the family can participate in caring for the patient.

The role of medical nutrition and hydration (also known as artificial nutrition and hydration - ANH) is not clear-cut. The patient's preferences, either declared at the time of treatment or previously documented in an advance directive, must be respected. In addition, the prognosis of a patient for the acute event, premorbid status, and religious and cultural factors warrant consideration [R].

In the context of a potentially treatable condition, ANH may support an individual who otherwise cannot meet nutritional needs during therapy.

A recent meta analysis of randomized clinical trials studying the effectiveness of nutritional supplementation (either oral, or via enteral or parenteral routes) identified no evidence for clinical benefit in a variety of clinical settings, including cancer, chronic lung or liver disease, and critical care settings [M].

There is no evidence that artificial nutrition and hydration improves outcomes in patients who have severe dementia. Most studies show that total parenteral nutrition in cancer patients receiving chemotherapy actually decreases survival and increases susceptibility to infection [R].

Constipation

Constipation is a common and troublesome symptom for seriously ill patients. Immobility, decreased oral intake, and medications, as well as underlying medical conditions themselves, can contribute to decreased gastrointestinal motility. As many as 95% of patients treated with opioids will experience constipation, and all opioids are associated with constipation. While tolerance to other opioid side effects such as nausea and sedation develops quickly, no tolerance develops to constipation [R].

Fiber supplements are not helpful in these patients, because they cannot achieve adequate fluid intake for them to be effective. Stool softeners and stimulant laxatives, such as bisacodyl and senna are almost always indicated, and patients on scheduled opioids should prophylactically and routinely receive them on a daily basis, unless contraindicated. Polyethylene glycol solutions have been shown to be effective and safe in the general population but have not been well studied in palliative care. Some patients, particularly those with neurogenic bowels, benefit from scheduled suppositories or enemas. Many commonly used agents lack high-quality evidence for effectiveness, but are widely used and generally have minimal toxicity [M], [R].

Patients taking opioids may exhibit additional gastrointestinal symptoms such as bloating, nausea, vomiting, and gastroesophageal reflux, along with constipation. This may represent opiate-induced bowel dysfunction, or opioid-induced constipation. This is a constellation of symptoms mediated through

peripheral mu receptors. Oral naloxone has been used. It has very poor bioavailability, but because it crosses the blood-brain barrier it may still cause reversal of analgesia. Newer opioid antagonists that do not cross the blood-brain barrier are in development but not yet clinically available, nor well studied in this population [M].

Delirium

Delirium is a clinical syndrome, not a disease in itself. Its etiology is usually multifactorial and includes central nervous system lesions, drugs, fluid and electrolyte abnormalities, hypoxia and other metabolic abnormalities. It is particularly prevalent in patients with preexisting dementia. Functional dependence, polypharmacy, sensory impairments and the existence of chronic health problems are factors increasing the risk for delirium.

Acute changes in mental status, with disorientation and fluctuations of attentiveness, are hallmarks of delirium. Patients often present with hyperactivity, agitation and combativeness. However, hypoactive delirium marked by lethargy is equally serious.

There are no specific tests, but evaluation should include review of all medications, especially psychoactive drugs: general physical evaluation, including vital signs, hydration status, and oxygenation; pain and recent alcohol or drug use. Particularly in elders, delirium may be the only harbinger of serious illness or complications. A focused search for infection, metabolic abnormalities and other acute illness is necessary.

Treatment of delirium requires correction of underlying abnormalities, as delirium may be reversible in up to 50% of cases in palliative care units. In some elderly patients delirium may be a result of poorly managed pain [R]. When behavioral symptoms threaten the safety of the patient or the ability to provide therapy, psychotropic medications may be used with caution. Haloperidol remains the first drug of choice, with the best evidence base supporting effectiveness. Lower doses are recommended in the elderly. There is little evidence supporting the use of other antipsychotic agents. Benzodiazepines are not recommended for monotherapy because of the risk of paradoxical stimulation, oversedation, and prolongation of delirium, but they can be useful adjuncts if haloperidol alone is not effective.

Note: the U.S. Food and Drug Administration informed health care professionals that the warnings regarding the use of haloperidol have been updated stating that Torsades de Pointes and QT prolongation have been observed in patients receiving haloperidol, especially when the drug is administered intravenously or in higher doses than recommended.

No good evidence exists for the use of other psychotropic drugs for delirium. Non-pharmacologic methods may also be beneficial, such as simple but firm communication, reassurance, reality orientation including an easily visible clock, and the presence of family members [R], although the effectiveness of these methods in the palliative care population has not been well studied.

Delirium is a poor prognostic indicator. In-hospital mortality rates for patients with delirium range from 22% to 76%, and the one-year mortality rates approach 40% [R].

Diarrhea

Diarrhea can be caused by the underlying illness, medications and infections. Diarrhea due to *Clostridium difficile* must be excluded. When present, this can be difficult to treat, and an individual may require retreatment if symptoms persist.

The presence of diarrhea does not exclude the possibility of bowel impaction, as the effect of gut flora on fecal material can cause liquefaction and subsequent passage of loose stool.

Dyspnea

Dyspnea can be defined as the subjective sensation of difficult breathing and is a common finding in patients with cancer, cardiac disease, advanced respiratory disease and AIDS. Neither the patient's respiratory rate nor the level of oxygenation consistently predicts the severity of dyspnea. A recent review found no well-validated measurement scales for this population [M]. The endpoint for managing dyspnea should be the patient's self-report of diminished breathlessness. Oximetry, pulmonary function tests, chest imaging and other diagnostic evaluations should be performed only if the results would change therapy.

Treatment of dyspnea should be focused on treatment of amelioration of the underlying cause, when possible, and managing symptoms.

Nonpharmacologic treatment may include repositioning, improving air circulation, maintaining cool room temperatures, psychological support and using relaxation techniques. Pharmacologic methods include oxygen, opioids and anxiolytics. Multiple published studies support the benefits of opioids for dyspnea. Opioids may decrease the ventilatory response to hypoxia and hypercapnia (in patients with these signs) and can decrease anxiety and the subjective sensation of shortness of breath without reducing oxygen saturation. Morphine is usually considered the opioid of choice for dyspnea in patients with cancer and may be administered by the oral, buccal, sublingual, subcutaneous or intravenous route. Limited information is available on nebulized morphine and its efficacy, and one must be cautious about possible bronchospasm with the first dose. Benzodiazepines, such as lorazepam, are useful when anxiety is a significant contributing factor. However, patients need to be monitored for sedation when combining benzodiazepines and opioids [R]. Inhaled corticosteroids may also be beneficial for patients who have an inflammatory component to their dyspnea (such as asthma or COPD) or have lung cancer.

Fatigue

Fatigue may be defined as decreased vitality in physical and/or mental functioning. Patients may identify increased tiredness, and state that rest fails

to resolve the fatigue. Fatigue may be a consequence of the primary illness or of the treatments used (such as radiation and chemotherapy).

There are assessment tools for fatigue; some examples include the Memorial Symptom Assessment Scale, the Edmonton Functional Assessment Tool, the Multidimensional Fatigue Symptom Inventory, and the Profile of Mood States.

Managing fatigue includes treating the underlying causes (such as anemia or hypoxia) if possible, as well as using nonpharmacologic and pharmacologic therapy directed toward the symptom itself. Nonpharmacologic treatment includes patient education about fatigue, modifying the activities of daily living, and scheduling rest periods during the day. Clinicians should counsel patients to prioritize activities and pace themselves accordingly. Mild exercise for brief periods may be beneficial in reducing the perception of fatigue for some patients.

Pharmacologic treatment of fatigue includes erythropoietin, psychostimulants and corticosteroids. Erythropoietin should be reserved for those patients with anemia and erythropoietin deficiency due to the high cost of treatment and lack of evidence of benefit in other clinical situations. Psychostimulants such as methylphenidate, dextroamphetamine and modafinil may be beneficial in managing fatigue and are the most commonly used pharmacotherapy for managing fatigue when no correctable underlying cause can be ascertained [R]. Due to significant side effects, corticosteroids should be reserved for terminally ill patients who may also have nausea and vomiting. Medications that may make the patient more tired should be administered at bedtime rather than in the morning. Conversely, stimulating agents should be administered in the morning.

Nausea and Vomiting

Nausea and vomiting can be very debilitating in patients with cancer, AIDS, and hepatic and renal failure. Nausea and vomiting can have a profound effect on quality of life, along with physical and mental function. Causes include drugs, gastrointestinal obstruction, uremia, psychological distress and vestibular stimuli. Triggers, such as smells and drugs, should be eliminated if possible.

Treatment consists of pharmacologic and nonpharmacologic treatment, while evaluating and treating the underlying cause. Nonpharmacologic treatment may include relaxation, acupuncture and transcutaneous electrical wave stimulation. However, the cornerstone of treatment is pharmacologic therapy, although there is a paucity of data on this subject in the palliative care population, and thus most of the support for certain treatments is based on expert opinion rather than primary studies [R]. Neurotransmitters implicated in nausea and vomiting include dopamine, serotonin, histamine and substance P; while peripherally, mechanoreceptors and chemoreceptors located in the gut, liver and viscera play an important role.

Dopamine antagonists used to treat nausea and vomiting include phenothiazines (prochlorperazine, promethazine) and butyrophenones (droperidol, haloperidol), which block dopamine either peripherally or

centrally. Metoclopramide may increase gastrointestinal motility in addition to being an antiemetic. Corticosteroids are effective as antiemetics themselves and may augment the effect of other antiemetics. Dronabinol appears to be better tolerated in younger patients. While serotonin receptor antagonists appear to be effective for acute nausea and vomiting due to chemotherapy, their indiscriminate overuse and increased cost is a significant issue.

Table. Suggested Medications Based on Cause of Nausea and Vomiting

Gastrointestinal Stimuli	Chemical Stimuli	Psychological Stimuli	Vestibular Stimuli
Metoclopramide	Metoclopramide	Benzodiazepines	Histamine antagonist
Serotonin antagonist	Corticosteroids	Dopamine antagonist	
Dopamine antagonist	Dopamine antagonist		
Proton pump inhibitors	Olanzapine		
	Histamine antagonist		
	Serotonin antagonist		

6. Cultural Aspects of Care

Key Points:

- Patient and family reactions to serious illness and decisions about end-of-life care are influenced by cultural factors.
- Specific cultural assessment promotes patient/family-centered decision-making and offers the opportunity to identify care preferences.
- Stereotyping should be avoided, as generalizations about specific cultures are not always applicable to specific patients.
- Whenever possible, the provider should utilize professional medical interpreters.

Patient and family reactions to serious illness and decisions about end-of-life care are influenced by cultural factors. Cultural assessment should be an integral component of the palliative care plan. The assessment should include:

- Locus of decision-making
- Preferences regarding disclosure of information
- Truth telling and decision-making
- Dietary preferences

- Language, family communication
- Perspectives on death, suffering and grieving
- Physical care of the deceased, funeral and burial rituals

Specific cultural assessment promotes patient/family-centered decision-making and offers the opportunity to identify care preferences.

With this in mind, providers should respect the important role culture plays in shaping the way people make meaning of illness, suffering, and dying and in guiding decisions people make about health care. But providers should avoid stereotyping and the assumption that they know what any one individual thinks or does because they assume they know what people of that group tend to think. There is, in fact, wide variation in beliefs, attitudes and behaviors within every cultural group [D].

Several key clinical recommendations that providers should consider have been identified [R]:

- Many ethnic groups prefer not to be directly informed of a life-threatening diagnosis.
- In cultural groups in which patients are not directly informed about a serious prognosis, family members may want the provider to discuss the patient's condition with family members only.
- When considering therapeutic options, providers should consider that members of many cultural groups prefer that family members, rather than patients, make treatment decisions.
- Direct discussions of advance directives and therapeutic support levels may be undesirable in situations in which they are viewed as potentially harmful to a patient's well-being.
- When provider-patient communication occurs through a translator, trained health care translators make fewer errors than untrained translators.

Whenever possible the provider should utilize professional medical interpreters. If medical interpreters are not available, the provider may need to use bilingual health care workers or family members. This, however, is less desirable due to misinterpretation of medical phrases, censorship of sensitive or taboo topics, and the tendency to filter or summarize discussions rather than translate them directly. The following recommendations are suggested for providers utilizing interpreters [D]:

- Meet briefly with interpreters prior to and after delivery of bad news or difficult discussions to help prepare the interpreter and to allow the interpreter to provide information about the patient, family and culture.
- Establish with the interpreter, patient and family members at the outset of a conversation or care conference that everything spoken will be translated word for word.
- After making a complete statement, providers should pause to allow for translation.

- Providers should speak to and look at the patient/family rather than the translator: "Where is your pain?" rather than "Can you ask him where he hurts?" [R].
- Consider meeting with the interpreter after the discussion to allow for any necessary debriefing.
- Use nonverbal forms of education such as drawing or showing pictures.
- Understand that not all tools (such as pain scales) are universal and providers need to use terms that are culturally relevant.
- Avoid using jokes or humor because they may be misunderstood or considered offensive.

A learning module on cultural and spiritual sensitivity and a quick guide to cultural and religious traditions can be found at this Web address:

<http://www.professionalchaplains.org/uploadedFiles/pdf/learning-cultural-sensitivity.pdf>.

The University of Washington's "Culture Clues" tip sheets contain information for clinicians about the needs and preferences of patients from diverse cultures: <http://depts.washington.edu/pfes/cultureclues.html>.

7. Psychological Aspects of Care

Key Points:

- Regular ongoing assessment of a patient's psychological status is important.
- Psychological treatment and interventions are based on goals in the plan of care.
- Difficulty in improving pain and other physical symptoms in spite of aggressive treatment can be a sign of significant psychological, emotional or spiritual issues.

Routine ongoing assessment of a patient's psychological status is critical to provide quality palliative care [R].

Pain and other physical symptoms are commonly the initial focus of treatment. Psychosocial issues are more difficult to evaluate and address if the patient has distressing or poorly controlled physical symptoms [R].

Patients come to advanced illness with issues of worry, insomnia, panic, anxiety, nervousness, paranoia and lack of energy. (See Annotation #5, "Physical Aspects of Care") Psychological symptoms may also present as physical symptoms such as pain, constipation, nausea and vertigo. Difficulty in improving physical symptoms should lead one to look at psychological or other causes. Practitioners must be aware of psychological symptoms of depression and anxiety. Use of standardized assessments to diagnose (e.g., Patient Health Questionnaire [PHQ-9]) may be helpful; however, no screening tool for depression has been validated for palliative care. Questions like "How are you coping?" "What are you doing to cope?" "Are you having trouble thinking?" "Are you depressed?" "Do you think about ending your own life?" or "Do you feel your situation is hopeless?" are good questions. Refer to the NGC summary of the ICSI guideline [Major Depression in Adults in Primary](#)

[Care](#) for more information about depression and the depression assessment tool (PHQ-9).

It is important to distinguish depressive disorders from normal grief. Neurovegetative signs such as somatic distress, sleep and appetite disturbances, and decreased concentration may occur as a result of the underlying illness, grief or depression. However, anhedonia, significant hopelessness, worthlessness, guilt and suicidal ideation strongly suggest depression [R].

More information can be found in the following Fast Facts at the Web site www.eperc.mcw.edu. #07 Depression in Advanced Cancer, #59 Dealing with the Angry Dying Patient, #145 Panic Disorders at the End of Life, and #186 Anxiety in Palliative Care-Causes and Diagnosis provide up-to-date easy to access references for psychological aspects of palliative care.

8. Social Aspects of Care

Key Points:

- The interdisciplinary team includes professionals with specific skills in assessment and development of a social care plan.
- Conduct care conferences specific to developing and reviewing the social care plan.
- Make referrals to meet social needs and remove barriers to care.

Recommendations:

- The interdisciplinary team of professionals including social workers should have patient-population specific skills in assessment and development of a social care plan.
 - The comprehensive assessment should include family structure and geographic location; relationships and family dynamics; lines of communication and need for counseling for self and family; existing social and cultural network; perceived social support; medical decision-making/Advanced Directives and quality of life; work and school settings; finances including filing for disability and ability to pay for medications and treatments; sexuality; intimacy; living arrangements; caregiver availability; access to transportation, medications, needed equipment and nutrition; community resources; and legal issues [R]
 - The comprehensive social care plan should address the social, practical and legal needs of the patient and caregivers based on the results of the comprehensive assessment outlined above [R]
- Conduct regular patient and family care conferences with the interdisciplinary team to develop and review the social care plan. Often the social worker is involved in coordinating this conference and its attendees. Further information and documents of support can be found at <http://www.capc.org/>. Also see Annotation #4, "Assessment of Patient's Palliative Care Needs and Values."

- Make referrals to meet identified social needs and to remove barriers to care. This includes but is not limited to transportation for treatment and appointments, caregiver service options to meet patient's needs at home, counseling, financial resources and community clubs/services for support.
- Understand that advance care planning is rarely fixed in time with specific treatment decisions but rather a dynamic process emerging from the clinical context of the disease and the social context of the patient [R]. Clear and honest communication, trust over time, and working within the patients' most important relationships are needed to improve the quality and outcome of this process.

9. Spiritual, Religious and Existential Aspects of Care

Key Points:

- Spirituality helps patients cope with illness, dying and death and contributes to improved quality of life [D].
- It is important for caregivers to attend to patients' spiritual needs and concerns. A spiritual assessment should be included in the overall plan of care.
- Utilize an interdisciplinary team with trained and credentialed chaplains to help provide patient-centered spiritual care and support.

Illness and the prospect of dying can impact the meaning and purpose of a person's life [R]. Thus illness and dying have a spiritual dimension and are often perceived by patients as spiritual experiences [D]. As people face serious illness or death, they often ask questions of meaning, value and relationships such as:

Meaning:

- Why is this happening to me? Why now?
- What is the meaning of my illness, my suffering, my death?
- What will happen to me after I die?

Value:

- Do I still have value despite changes in my appearance, productivity, independence?
- Is there anything valuable about me that will persist beyond death?

Relationships:

- Do I need to forgive or be forgiven by anyone?
- Am I loved? By whom?
- Will I be remembered after I die? Will I be missed? [R], [X]

Other spiritual issues and concerns encountered in palliative care include: life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness, legacy, and life completion tasks [R].

It is important for caregivers to attend to patient's spirituality, especially any spiritual concerns, questions or distress. A 1997 survey by the Gallup Institute found that people overwhelmingly want their spiritual needs addressed during their dying process. Spirituality is an important but often neglected component in holistic care of patients.

Physicians and other care providers can attend to patient's spiritual needs and concerns in the following ways [D]:

- Offer compassionate presence – strive to be present with and attentive to patients. Relate to patients not only as a professional expert but also as a fellow human being.
- Listen to patient's fears, hopes, pain and concerns – listening is a powerful healing tool.
- Assess spiritual needs and concerns – asking patients about hope and peace [D] is a simple, brief yet effective way to assess spiritual concerns.
 - Do you have hope?
 - Where does your hope come from?
 - What are you hoping for now as you look ahead?
 - Are you at peace with the care decisions you've made?
 - Do you feel at peace – in your heart, your spirit?
 - Where does peace come from for you?
 - Does that peace come from a spiritual or religious source? [X]
- There are a number of spiritual assessment tools created for use by providers in the clinical setting. Some of these tools include:

H: Sources of hope, meaning, comfort, strength, peace, love, connection

O: Member of an organized religion?

P: Personal spirituality, practices

E: Effects of beliefs on medical care and end-of-life issues

[R]

F: Do you have spiritual beliefs or Faith that have helped you cope with difficult times in the past?

I: Are these beliefs important to you, and how do they Influence the way you care for yourself?

C: Are you involved in a spiritual or religious Community or Church?

A: How would you like your health care providers to help you Address spiritual issues and concerns?

[R]

S - Spiritual belief system

P - Personal spirituality

I - Integration with a spiritual community

R - Ritualized practices and restrictions

I - Implications for medical care

T - Terminal events planning

[R]

- Utilize clinically trained chaplains as members of the interdisciplinary health care team – chaplains are experts in spiritual care. They offer interfaith support to all who are in need and have specialized education to mobilize spiritual resources to help patients cope more effectively *[R]*. Working with and making referrals to these spiritual care providers is an important aspect of holistic care.

Physicians and other providers should always be respectful of a patient's spiritual beliefs, should keep spiritual discussions patient centered, and should never proselytize or impose beliefs onto a patient *[R]*, *[X]*.

10. Ethical and Legal Aspects of Care

Key Points:

- Advance care planning, including advance directives and appointing a health care proxy, may be helpful in documenting and ensuring that a patient's wishes will be respected.
- The patient's goals, preferences and choices are respected within the limits of applicable state and federal laws, and form the basis for the plan of care.
- Informed consent for any treatment or plan of care requires a patient with decision-making capacity or an appropriate surrogate decision-maker.

The patient's goals, preferences and choices should form the basis for the plan of care. They should be respected within the limits of applicable state and federal laws. Informed consent for any treatment or plan of care requires a patient with decision-making capacity or an appropriate surrogate decision-maker. Informed consent is based on the principle that patients should be allowed to make decisions for themselves. Decision-making capacity thus serves as a gatekeeper concept. A surrogate is needed for patients who lack decision-making capacity.

Note: Competency is a legal term referring to a decision made by a judge, although a physician's opinion carries a large amount of weight in a competency hearing. In contrast, **decision-making capacity** (a.k.a. decisional) refers to a physician's determination, based on clinical examination, that a patient is able to make medical decisions relative to the discussion for

themselves. Most state power of attorney for health care documents require a physician to document that a patient has lost decision-making capacity for the surrogate to become the legal agent for medical decisions.

To be deemed **decisional**, a physician must be satisfied that a patient is able to:

- Receive information (e.g., must be awake, but not necessarily oriented)
- Evaluate, deliberate and mentally manipulate information and
- Communicate a treatment preference (i.e., the comatose patient by definition is not decisional)

Refer to the original guideline document for definitions of "decision-making capacity" and "medical futility."

Physicians are not legally, professionally or ethically required to offer medically futile treatments, **as defined by the standard of care of the medical community**. Ethics committees, hospitals and local/state medical organizations can provide resources to understand medical futility and professional responsibilities in one's practice area.

Suggestions

- Check with your health care institution about the presence of an existing futility policy.
- Avoid using the term "futility" in discussion with patients/families; rather, speak in terms of benefits/burdens of treatment and patient- or family-specific goals of care.
- Involve a palliative care and/or ethics consultant in any situation where "futility" will be invoked as a process step in formulating decisions [R].

Advance Directives

Advance care planning, including advance directives and appointing a health care proxy, may be helpful in documenting and ensuring that a patient's wishes will be respected. Written advance directives are legal in every state; however, laws and forms vary state to state. See Other Resources section in the original guideline document for additional information regarding advance directives. It is important to remember that travelers should be aware of differing laws in whichever state they plan to travel, and bring a copy of their document with them.

There are two types of advance directives:

- **Health care power of attorney** (aka: durable power of attorney for health care, health care agent, etc.) – a document in which the patient appoints someone to make decisions about his/her medical care if he/she cannot make those decisions. This is also known as a "living will."

- **Health Care Directive** – a written document in which a patient's wishes regarding the type or extent of medical treatment to be administered or withheld are described if the patient becomes unable to communicate his/her preferences.

The POLST (Physician's Order for Life-Sustaining Treatment) is one form of a health care directive that was designed to help health care providers honor the treatment wishes of patients in the form of an actual physician order. It is becoming more widespread in its acceptance in many parts of the country. POLST was developed as a one-page, advance care planning document, to be completed by health care professionals, together with a patient or surrogate decision-maker. The actual form should consist of these sections:

- Cardiopulmonary resuscitation (CPR) decision
- Medical intervention decisions
- Antibiotics
- Medically administered nutrition
- Signatures from the health care professional and if possible, the patient/surrogate

[R]

The major advantages of the POLST form over standard advance directives is that, when adopted as the community standard, the information is clear, unambiguous, flexible, portable, available across all sites of care, and more likely to be honored by all health care providers when needed (www.polst.org, 2008).

Barriers to Completing Advance Directives

- Many physicians believe it is not appropriate to begin advance directive planning on an outpatient basis. In reality, multiple studies have shown that **patients want their doctors to discuss advance care planning** with them **before** they become ill. Many others have shown a positive response from patients when advance directive discussions are held during outpatient visits.

Overcoming this barrier: When beginning a discussion of advance directives simply ask, "Do you know what an advance directive is? Do you have one?" If you are afraid the patient may respond negatively, perhaps saying to you, "Doc, is there something wrong with me? Am I sicker than you are letting on?" respond by saying, "I ask all of my patients this question, sick or well." The Patient Self-Determination Act of 1991 mandates that every person be asked about advance directives when first seen (inpatient and outpatient).

- Many people believe that if a loved one has financial power of attorney, he/she doesn't need a separate medical power of attorney. This is not true. **Most often these are separate legal documents.**

Overcoming this barrier: When discussing power of attorney with your patient, assess his/her understanding. Have literature in your office to clear up discrepancies.

- Many physicians and patients feel that having an advance directive means "Don't treat." Unfortunately, advance directives can be a trigger for disengagement by the medical staff.

Overcoming this barrier: Make sure your patient and staff understand that advance directives don't mean "Don't treat me." **They mean, "Treat me the way I want to be treated."**

- Patients often fear that once a person names a proxy in an advance directive he/she loses control of his/her own care.

Overcoming this barrier: When explaining advance directives to your patients, make sure he/she understand that as long as he/she retains decision-making capacity, he/she retains control of their medical destiny. **Advance directives only become active when a person cannot speak for himself or herself.**

- Many people believe that only old people need advance directives.

Overcoming this barrier: The stakes may actually be higher for younger people if tragedy strikes. Use the example of the Terry Schiavo case as a trigger to enlighten the discussion. Ask "What would you want if you were in a similar situation?"

[R]

Six Steps for Writing Do-Not-Resuscitate (DNR) Orders

1. The physician makes a benefit/burden assessment of CPR in the context of the patient's overall prognosis.
2. If the assessment is negative, the physician consults with other members of the health care team about the issue and discusses the need for a DNR order.
3. If there is no remaining substantive objection, the physician approaches the patient (if capable) or the designated decision-maker(s) (if the patient is incapacitated) and explains a DNR order and why the health care team recommends writing such an order.
4. If no substantive objection is made, the physician writes the order in the patient's chart, documenting the discussion and the reasons for the DNR order in the progress notes of the chart.
5. The DNR order is reviewed regularly.
6. The DNR order can be revoked if the benefit/burden assessment changes.

[R]

11. Care of Imminently Dying Patient

Key Points:

- Recognition of the dying phase is essential.
- There is less anxiety and depression if the dying process is clearly discussed.
- Ongoing communication with the patient and family regarding the dying process and the treatment plan is necessary.
- Ongoing revision of the plan of care must be individually directed to the patient and family.

Care of the imminently dying patient is an intense interval for the patient, family and the health care team. Initiating discussion with the patient and family is the first step in establishing the individual plan of care for the dying patient [M]. This allows for clarification of prognosis, identification of end-of-life goals, and identification of care preferences [R].

The patient's transition to the dying phase should be consistently communicated by all members of the health care team. Mixed messages should be avoided as they can lead to loss of trust, miscommunication and poor care management [R]. The National Consensus Project Clinical Practice Guidelines and the National Comprehensive Cancer Network Advance Care and Palliative Care Treatment Guidelines for Patients both endorse open communication with the patient, family, and care team regarding the dying phase and plan of care [R].

Care of the imminently dying patient requires an intensive plan of care. Essential to this plan is recognition of the dying patient. Recognizing the dying patient requires a set of clinical skills. There are key signs and symptoms that indicate that death will occur in hours to days. Patients and family members need clear information about the physical and psychological aspects of the dying process. Diagnosing dying is complex and at times uncertain. Agreement between care team members that the patient is dying, and communicating this to the patient and family improves satisfaction and fosters trust [R].

Establishing a treatment plan takes into account individual and family goals and preferences. It is ideal to have this treatment plan available at the point of care, regardless of the site of care (inpatient, outpatient or emergency department [ED]). The work group recognizes there are barriers to availability of the treatment plan due to limitations of communication within access and care systems [D].

The treatment plan should include education for the patient and family. This education should include the signs and symptoms of imminent death. Attention to developmental, cultural and religious needs is critical. Patient and family wishes regarding the site of death should be discussed. Studies show that from 70% to 90% of people indicate that they prefer to die at home; despite this, about 75% of all deaths in the United States occur in hospitals or nursing homes [R]. Referral to a hospice program may be appropriate.

The comprehensive treatment plan must be medically sound and concordant with the patient's wishes and values [R]. Attention to adequate symptom

management allays fears and allows comfort during the dying process. The treatment plan includes physical, psychological, social and spiritual care [M]. Ongoing communication remains central. A comfort care order set may be beneficial for practitioners to use for imminently dying patients. See ICSI Palliative Care Order Set.

12. Develop or Revise Palliative Care Plan

Use a "shared decision-making" model if appropriate. This model promotes collaboration between the physician and patient in making treatment decisions, where the physician shares information and knowledge about the treatment options and the patient uses his or her values to weigh the risks and benefits of the different care options. Note that this does not preclude the physician making a strong treatment recommendation based on clinical knowledge and experience. However, level of interest in medical information tends to be stronger with younger age and increased educational attainment; older patients may prefer less information and want to rely more on the physician's expertise alone. More acutely ill patients may have limited ability to successfully weigh risks and benefits of the different options and thus may rely more on family members or on the physician's recommendation. This underscores the need to individualize care option discussions to patient preferences and illness status [R]. Discussions on treatment preferences should be periodically revisited to account for changes in patient preferences and course of illness, especially given that treatment strategies at one stage of the illness may be inappropriate for another stage [R].

Although patients and family members desire a say in treatment options, the physician should make a clear recommendation based on his or her expertise and experience [D], [R]. It is important that the patient does not feel rushed into deciding between treatment options, as he or she may need to digest the initial bad news first [R].

13. Does Patient Meet Hospice Criteria?

Key Points:

- Hospice care, now available in most communities in the United States, offers palliative medical care from a multidisciplinary team and serves patients and families as a unit with emotional, social and spiritual support.
- Medicare patients certified by their physician as terminally ill with a life expectancy of six months or less if the disease runs its expected course may elect to receive hospice care. Most private insurances now have hospice benefits, although coverage may vary.
- Discharge from hospice occurs if prognosis improves or if the patient wishes to seek curative treatment.
- A patient may be readmitted at any time, as long as the criteria for hospice are met.

See Appendix A, "Comparison between Palliative Care and Hospice," in the original guideline document for a table outlining symptoms and conditions relative to palliative and hospice care settings.

Refer to the original guideline document for information about Medicare Hospice Benefit (MHB): Eligibility and Treatment Plan.

Plan of Care (POC)

The hospice team and the patient's physician work together with the patient and family to maximize quality of life by jointly developing the POC. The POC is based on the patient's diagnosis, symptoms and goals of care. The hospice program and the patient's physician must together approve any proposed tests, treatments and services. In general, only those treatments that are necessary for palliation and/or management of the terminal illness will be approved.

Physician Role

At the time of enrollment, the patient indicates the primary physician who will direct care; the patient may select a hospice physician for this role or may select his/her usual primary doctor. The primary physician is responsible for working with the hospice team to determine appropriate care.

Places of Care

Home. The majority (95%) of hospice care takes place in the home. Hospice team members visit the patient and family on an intermittent basis, determined by the Plan of Care. Medicare rules do not require a primary caregiver in the home, but as death nears, it becomes increasingly difficult to provide care for a patient who does not have someone (family, friends, hired caregivers) who can be present 24 hours a day in the home.

Long-term Care Facility. 25% of patients in the U.S. die in nursing homes. Medicare recognizes that this can be the resident's home and that the patient's family frequently includes the nursing home staff. Hospice care under the MHB can be provided to residents in addition to usual care provided by the facility. Individual hospice programs must establish a contract with the facility to provide hospice care. The MHB does not pay for nursing home room and board charges.

Hospice Inpatient Unit. Dedicated units, either free-standing or within other facilities, such as nursing homes or hospitals, are available in some areas. Permitted length of stay varies with the facility and its specific admission policies.

General Inpatient Facility. When pain or other symptoms related to the terminal illness cannot be managed at home, the patient may be admitted to a hospital or inpatient facility for more intensive management, still under the MHB. The inpatient facility must have a contract with the hospice program for acute care.

Emergency Department/Urgent Care

Patients may seek medical care at EDs or urgent care centers when unable to manage their care independently at home. It is essential that any testing or treatment be coordinated with the hospice team.

[R]

For specific Medicare Hospice Benefit information see <http://www.cms.hhs.gov/center/hospice.asp>.

15. Hospice Care Team Coordinates Care with Primary Provider

At the time of enrollment, the patient indicates the primary physician who will direct care. The patient usually selects the primary specialty care physician who is currently directing his/her care but may elect to have the hospice medical director as the primary physician in certain cases. The hospice team works with the primary physician and patient and family to determine appropriate care. (See Annotation #13, "Does Patient Meet Hospice Criteria?")

"All hospice is palliative care, but not all palliative care is hospice" (<http://www.wisconsinhospice.org/whatishospice.cfm>).

- Although the palliative care model (see original guideline document) encompasses hospice care, it is beyond the scope of this guideline to include all aspects of care once the patient is admitted to hospice.
- Discharge from hospice may occur for several reasons. These may include:
 - An improved prognosis
 - The patient wishes to seek curative treatment, or
 - An unrelated problem forces the patient to disenroll in hospice

Patient may be readmitted to hospice at any time, as long as the criteria for admission are still met. (See Annotation #13, "Does Patient Meet Hospice Criteria?")

To determine whether a Medicare-approved hospice program is available in your area, contact the nearest Social Security Administration office, your state or local health department or your state hospice organization (in Minnesota, Hospice Minnesota (800) 214-9597), or call the National Hospice Organization Hospice Help Line (800) 658-8898.

16. Make Palliative and/or Specialty Care Referrals and/or Consults as Needed

Key Points:

- Advanced care needs assessment and care planning place great demands on a busy practitioner.
- Specialist referral may be useful or counterproductive.
- Community-based palliative care service promotes consistent communication and delivery of care.

When available in the community, it may be appropriate to refer to a palliative care service. In other communities, local hospice care team members may provide palliative care. The evidence-based medicine support for the value of palliative care referral has been only marginally positive, in great measure due to ethical and logistical problems with recruitment of research subjects. What research does exist includes improved symptom control and quality of life [C], [M]; improved utilization of limited resources including decreased intensive care unit [ICU]/emergency room [ER] use; decreased length of stay [LOS]; increased acute care capacity [C], [D], [R]; and improved satisfaction of patients, families and health care providers [B], [R].

Often the busy practitioner wants to "be there" for the patient but cannot "do it all." Referral to specialists for consultation may be quite helpful but – in the absence of a thorough understanding of the patient's overall condition, needs and values – may result in recommendations for diagnostic/therapeutic interventions that the patient finds more burdensome than beneficial [R]. It is important to educate staff in all settings (i.e., ED, outpatient clinic and inpatient) regarding appropriateness of palliative care referrals.

Refer to the original guideline document for more information on the value of community-based palliative care services.

20. Remission or Resolution of Disease?

While palliative care is delivered across care settings and throughout the full course of illness, a patient may no longer require focused palliative care when:

- There is a remission of symptoms and the illness is no longer progressing
- The disease process is resolved (cured)
- Death occurs

If symptoms recur or the patient's condition deteriorates, a new evaluation of the patient's palliative care needs should be done; therefore, they would reenter the care process at box #4 of the algorithm (see the original guideline document).

22. Death and Bereavement

Key Points:

- Health care providers play an important role in facilitating healthy grief and bereavement processes.
- Various factors may predispose an individual to complicated grieving.
- Many community services are available to the bereaved.

Grief is the emotional suffering caused by a significant loss, such as the death of a loved one that includes both physiologic and psychological reactions [D]. Grief can be anticipatory, such as that experienced by the patient or a loved

one prior to the expected death of the patient [R]. Grief can also be complicated, leading to maladaptive behaviors associated with a distorted or prolonged grief period [D]. Grief following a death is called bereavement. However, bereavement interventions can begin prior to and in anticipation of the actual loss [R].

Health care providers play an important role in facilitating healthy grief and bereavement processes. Honesty at the end of life is essential (see Annotation #3, "Initiate Palliative Care Discussion"). By avoiding mixed messages, patients may review their lives and assist loved ones in future plans. At this time it may be possible to identify bereavement needs of patients and their loved ones. By assessing the grief response prior to death, it is possible to identify risk of complicated grieving and provide early intervention [D].

Following the death of the patient, it is essential to allow the patient's loved ones to perform any customs or rituals that are important to them, within the policy guidelines of the facility. Failure to do so may lead to complicated grieving [M]. Providers should be available to answer questions and offer support. This may be done informally or through a formal debriefing.

Provider contact after the death of a patient can be comforting for the patient's loved ones [M]. Providers may wish to offer emotional support by sending a card expressing their condolences. Providers should also offer practical support by completing death certificates in a timely manner, filling out necessary forms or writing letters for the family as needed.

Several models defining grief are available, yet it is important to note that progress through grief is not predictable. Movement through grief varies from person to person, and the bereaved may vacillate between stages, or elements of stages may appear concurrently. **Grief is not on a linear continuum and does not follow a specific time frame.** In complicated grieving, the person may fail to progress through grief or may be "stuck" in one stage of the grief process.

Several factors may predispose an individual to complicated grief. These include:

- Dependent or ambivalent relationship
- Multiple previous bereavements
- Previous psychiatric history, especially depression
- Sudden and unexpected death
- Death of a young person
- Stigmatized deaths such as suicide or AIDS
- Culpable deaths
- Inability to carry out valued religious rituals
- Lack of social support
- Survivor under age 45 whose partner died suddenly, or over 65 whose partner had illness of five years or more
- Multiple life crises
- Sex of bereaved person – (e.g., elderly male widower)

[R], [Not Assignable]

Others who are vulnerable to complicated grief include children, confused elders and those with learning disabilities. Many resources are available for children, including storybooks, workbooks and a regional camp for grieving children. For confused elders or survivors with learning disabilities, repeated explanations and participation in important events, such as the funeral, may decrease the repetitious questions about the deceased *[Not Assignable]*.

In order to provide support through the first anniversary of the death, it is suggested that the length of follow-up with the bereaved is a minimum of thirteen months *[D], [R]*. Bereavement counseling is required by Medicare for hospice programs, yet two thirds of patients die out of hospice services *[Not Assignable], [R]*. Although it is not realistic for health care providers to personally provide bereavement services for the grieving loved ones of a patient, it is imperative that each provider be aware of the needs of the bereaved, potential risk factors for complicated grieving and the services available within their area so that appropriate referrals can be made to promote healthy grieving. Possible community services include pastoral care, support groups, counseling services, grief groups, bereavement follow-up programs and communities of faith. A referral to social services or contacting a local hospice program would be appropriate for assistance in bereavement interventions.

Definitions:

Classes of Research Reports

A. Primary Reports of New Data Collection:

Class A:

- Randomized, controlled trial

Class B:

- Cohort study

Class C:

- Non-randomized trial with concurrent or historical controls
- Case-control study
- Study of sensitivity and specificity of a diagnostic test
- Population-based descriptive study

Class D:

- Cross-sectional study
- Case series
- Case report

B. Reports that Synthesize or Reflect upon Collections of Primary Reports:

Class M:

- Meta-analysis
- Systematic review
- Decision analysis
- Cost-effectiveness analysis

Class R:

- Consensus statement
- Consensus report
- Narrative review

Class X:

- Medical opinion

CLINICAL ALGORITHM(S)

A detailed and annotated clinical algorithm is provided for [Palliative Care](#).

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is classified for selected recommendations (see "Major Recommendations").

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Improved palliative care resulting in facilitating appropriate discussions with patients and family; improved symptom control and quality of life; improved utilization of resources; and improved satisfaction of patients, families, and health care providers

POTENTIAL HARMS

Advance directives can be a trigger for disengagement by the medical staff.

Adverse Effects of Medications

- *Benzodiazepines* are associated with the risk of paradoxical stimulation, oversedation, and prolongation of delirium.

- *Progestational agents* may be associated with an increased risk of thromboembolic events, peripheral edema, hyperglycemia, hypertension, hypogonadism, and adrenal suppression.
- Because of significant side effects, *corticosteroids* should probably be reserved for the terminally ill, and in those patients who may simultaneously benefit from the antiemetic and analgesic properties of the steroids.
- As many as 95% of patients treated with *opioids* will experience constipation, and all opioids are associated with constipation. While tolerance to other opioid side effects such as nausea and sedation develops quickly, no tolerance develops to constipation. Patients taking opioids may exhibit additional gastrointestinal symptoms such as bloating, nausea, vomiting, and gastroesophageal reflux, along with constipation.
- The U.S. Food and Drug Administration (FDA) informed health care professionals that the warnings regarding the use of *haloperidol* have been updated stating that Torsades de Pointes and QT prolongation have been observed in patients receiving haloperidol, especially when the drug is administered intravenously or in higher doses than recommended.

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

- These clinical guidelines are designed to assist clinicians by providing an analytical framework for the evaluation and treatment of patients, and are not intended either to replace a clinician's judgment or to establish a protocol for all patients with a particular condition. A guideline will rarely establish the only approach to a problem.
- This clinical guideline should not be construed as medical advice or medical opinion related to any specific facts or circumstances. Patients are urged to consult a health care professional regarding their own situation and any specific medical questions they may have.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Once a guideline is approved for general implementation, a medical group can choose to concentrate on the implementation of that guideline. When four or more groups choose the same guideline to implement and they wish to collaborate with others, they form a guideline action group.

In the action groups, each medical group sets specific goals they plan to achieve in improving patient care based on the particular guideline(s). Each medical group shares its experiences and supporting measurement results within the action group. This sharing facilitates a collaborative learning environment. Action group learnings are also documented and shared with interested medical groups within the collaborative.

Currently, action groups may focus on one guideline or a set of guidelines such as hypertension, lipid treatment and tobacco cessation.

Detailed measurement strategies are presented in the original guideline document to help close the gap between clinical practice and the guideline recommendations. Summaries of the measures are provided in the National Quality Measures Clearinghouse (NQMC).

Key Implementation Recommendations

The following system changes were identified by the guideline work group as key strategies for health care systems to incorporate in support of the implementation of this guideline.

1. Develop a process to provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care. It is important to address the difference between palliative care and hospice.
2. Develop a process that will allow providers to identify and assess patients who would benefit from palliative care services. This process should include the use of a screening tool that utilizes the seven domains.
3. Develop scripts for health care providers that will assist them in initiating and discussing palliative care services.
4. Develop a process for timely referral to palliative care consultation for patients with a progressive, debilitating disease.

IMPLEMENTATION TOOLS

Clinical Algorithm
Patient Resources
Pocket Guide/Reference Cards
Quality Measures
Quick Reference Guides/Physician Guides

For information about [availability](#), see the "Availability of Companion Documents" and "Patient Resources" fields below.

RELATED NQMC MEASURES

- [Palliative care: percentage of adult patients with a progressive, debilitating disease who have a palliative care plan documented in the medical record.](#)

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Institute for Clinical Systems Improvement (ICSI). Palliative care. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI); 2008 May. 58 p. [113 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

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2007 Jan (revised 2008 May)

GUIDELINE DEVELOPER(S)

Institute for Clinical Systems Improvement - Private Nonprofit Organization

GUIDELINE DEVELOPER COMMENT

Organizations participating in the Institute for Clinical Systems Improvement (ICSI): Affiliated Community Medical Centers, Allina Medical Clinic, Altru Health System, Aspen Medical Group, Avera Health, CentraCare, Columbia Park Medical Group, Community-University Health Care Center, Dakota Clinic, ENT Specialty Care, Fairview Health Services, Family HealthServices Minnesota, Family Practice Medical Center, Gateway Family Health Clinic, Gillette Children's Specialty Healthcare, Grand Itasca Clinic and Hospital, HealthEast Care System, HealthPartners Central Minnesota Clinics, HealthPartners Medical Group and Clinics, Hutchinson Area Health Care, Hutchinson Medical Center, Lakeview Clinic, Mayo Clinic, Mercy Hospital and Health Care Center, MeritCare, Mille Lacs Health System, Minnesota Gastroenterology, Montevideo Clinic, North Clinic, North Memorial Care System, North Suburban Family Physicians, Northwest Family Physicians, Olmsted Medical Center, Park Nicollet Health Services, Pilot City Health Center, Quello Clinic, Ridgeview Medical Center, River Falls Medical Clinic, Saint Mary's/Duluth Clinic Health System, St. Paul Heart Clinic, Sioux Valley Hospitals and Health System, Southside Community Health Services, Stillwater Medical Group, SuperiorHealth Medical Group, University of Minnesota Physicians, Winona Clinic, Ltd., Winona Health

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GUIDELINE COMMITTEE

Committee on Evidence-Based Practice

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The Institute for Clinical Systems Improvement (ICSI) has adopted a policy of transparency, disclosing potential conflict and competing interests of all individuals who participate in the development, revision and approval of ICSI documents (guidelines, order sets and protocols). This applies to all work groups (guidelines, order sets and protocols) and committees (Committee on Evidence-Based Practice, Cardiovascular Steering Committee, Women's Health Steering Committee, Preventive & Health Maintenance Steering Committee, Respiratory Steering Committee and the Patient Safety & Reliability Steering Committee).

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No work group members have potential conflicts of interest to disclose.

GUIDELINE STATUS

This is the current release of the guideline.

This guideline updates a previous version: Institute for Clinical Systems Improvement (ICSI). Palliative care. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI); 2007 Jan. 49 p.

GUIDELINE AVAILABILITY

Electronic copies: Available from the [Institute for Clinical Systems Improvement \(ICSI\) Web site](#).

Print copies: Available from ICSI, 8009 34th Avenue South, Suite 1200, Bloomington, MN 55425; telephone, (952) 814-7060; fax, (952) 858-9675; Web site: www.icsi.org; e-mail: icsi.info@icsi.org.

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Palliative care. Executive summary. Bloomington (MN): Institute for Clinical Systems Improvement, 2008 May. 1 p. Electronic copies: Available from the [Institute for Clinical Systems Improvement \(ICSI\) Web site](#).
- ICSI pocket guidelines. May 2007 edition. Bloomington (MN): Institute for Clinical Systems Improvement, 2007.

Print copies: Available from ICSI, 8009 34th Avenue South, Suite 1200, Bloomington, MN 55425; telephone, (952) 814-7060; fax, (952) 858-9675; Web site: www.icsi.org; e-mail: icsi.info@icsi.org.

PATIENT RESOURCES

The following is available:

- Palliative Care. Bloomington (MN): Institute for Clinical Systems Improvement, 2007 May 43 p. Available in Portable Document Format (PDF) from the [Institute for Clinical Systems Improvement \(ICSI\) Web site](#).

NGC STATUS

This NGC summary was completed by ECRI on April 4, 2007. This summary was updated by ECRI Institute on July 9, 2007, following the FDA advisory on erythropoiesis stimulating agents. This summary was updated by ECRI Institute on October 2, 2007, following the U.S. Food and Drug Administration (FDA) advisory on Haloperidol. This summary was updated by ECRI Institute on November 6, 2007, following the U.S. Food and Drug Administration advisory on Provigil (modafinil) Tablets. This summary was updated by ECRI Institute on November 9, 2007, following the U.S. Food and Drug Administration advisory on Antidepressant drugs. This summary was updated by ECRI Institute on March 21, 2008 following the FDA advisory on Erythropoiesis Stimulating Agents. This summary was updated by ECRI Institute on July 23, 2008.

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